

Witness Name: **GRO-B**

Statement No: WITN1512001

Exhibits: 0

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** and I live at **GRO-B**.
GRO-B My date of birth is the **GRO-B**. I got married in **GRO-B** and we have no children. I am retired on medical grounds. I am currently studying a master's degree in English Literature.
2. My mother, **GRO-B** has produced a witness statement to the Inquiry ('**WITN2804001**').
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

4. I suffer from severe Haemophilia A. I suffered from head bleeds when I was a baby which resulted in swelling. I was misdiagnosed with Von Willebrand disease and following this misdiagnosis I was correctly diagnosed with Haemophilia A when I was approximately 4 years old. I am the first haemophiliac in my family. My mother and sister are both Haemophilia carriers.
5. Initially I was treated with Cryoprecipitate drips which involved long visits at the hospital. I started receiving Factor VIII concentrate (FVIII) when it became available in or about the mid/late 1970s. I remember this because I just started the FVIII treatment prior to us moving to **GRO-B** for a short period of time whilst my father was in the army.

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6. I believe I started to receive FVIII at a hospital in [GRO-B]. However, I do not believe they had a Haemophilia Centre. I therefore attended the [GRO-B] and received FVIII treatment. I was under the care of [GRO-B] and [GRO-B].
7. From [GRO-B] I attended Treloar's College, where I was also treated with FVIII.
8. I do not believe that my mother was provided with any information or advice about the risk of being exposed to infection from the blood products.
9. As a result of using contaminated FVIII, I was infected with Hepatitis A (Hep A), Hepatitis B (Hep B), Hepatitis C (Hep C) and HIV. I do not know precisely when or which batch of FVIII infected me but believe it to be around 1980, as when I was informed of my infected status I was also told I had been infected for seven years. At this meeting I was given no information about the Hepatitis infections, of which I was also a carrier.
10. In or about the mid/late 1980s I was called into a consultation room of the sick bay area by my teacher at the Treloar's College. I was then told by Dr Aronstam, a Haematology Consultant that I was HIV positive. I had a girlfriend and I believe this was predominantly why I was told. In a brief meeting with Dr Aronstam he questioned why I had never asked about my infected status. I was blasé and asked whether I was positive to which he responded "Yes you are". He went on to tell me that the life expectancy for HIV positive patients was no more than 10 years. It was a death sentence. Being told this was the first and last time I have every felt a physical reaction to words; it was like being punched in the face, I remember clearly rocking back in my chair.
11. When I was approximately [GRO-B] years old, at a routine check-up I found out that I also had Hep A and Hep B. I was vaccinated for both of them at the [GRO-B].
12. Approximately [GRO-B] or [GRO-B] years ago I received a letter from the [GRO-B] stating that I had Hep C but I was not invited for a follow-up consultation. It turns out that I was tested before [GRO-B] but not told until about [GRO-B] years ago. The doctors therefore knew that I was infected with Hep C, but failed to tell me. I should have been told about this infection as soon as the doctors knew about it.
13. I was not provided with adequate information in relation to how to manage or understand the above infections.
14. I was not provided with any information in relation to risks of transmission. However, I assume they knew about the risks as they decided to tell me at a point when my girlfriend and I started becoming very close.
15. I believe that the doctors knew about the HIV virus years before I had been told. I think they were covering their own backside and if they were concerned about my age at the time I

believe they should have disclosed this information to my parents as soon as they were aware of my positive test results. I don't believe that any information should be censored and not telling, whatever their rational was selfish and cruel.

16. The results were not really '*communicated*' to me. Their attitudes in respect of the Hepatitis and HIV was matter-of-fact: "*This is your life, jog on*".
17. I do think they played the infections down significantly, although now more information is available. My friends and I always believed there was something going on behind the scenes. Those friends are sadly no longer with me. I strongly believe they wanted to wait for all of the haemophiliacs to drop dead so this problem would disappear and if not for the advancement in treatment this would have been the case.

Section 3. Other Infections.

18. Approximately GRO-B years ago, around the same time that I found out I had Hep C, I also received a letter stating that I was at risk of being exposed to vCJD. Following this letter I received no more information and once again there was no follow up consultation.

Section 4. Consent.

19. I was certainly tested without my knowledge as I did not find out about my infections until years after being tested.
20. I knew I was being treated with FVIII concentrate after Cryoprecipitate.
21. I believe that the doctors had knowledge about the possibility of infections in FVIII products. I distinctly remember when a Doctor Wasif at Treloar's College dropped a vial of FVIII on the floor, which broke. I recall that he spent a lot of time cleaning the mess up off the floor and I said "that's a bit extreme" and he said that we had to be very careful because this is the stuff which carried all the infections. Of course, he still gave me the other vials from the same batch.
22. I was certainly tested without my consent and I believe I was tested and treated without being given adequate information.
23. I know that I was given pig's blood at one point and therefore believe that I was tested for purposes of research. The doctors at Treloar's College told a group of us that we were involved in a trial and we were their guinea pigs.

Section 5. Impact

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24. In order to survive and cope with having to live with the infections, I try not to look into them too much. I would not be able to function if I became consumed with the fact that I had been infected as a result of contaminated blood products, the same treatment that was suppose to save my life. I think if I was submerged into all of this I would have jump off a bridge. I live each day as it comes and this is my way of coping.
25. I have struggled mentally because of the infections and I have been in denial throughout my life until I met my wife. I got married at the age of [GRO-B] I denied myself any physical or emotional contact in a relationship out of fear. I would not be able to live with myself if I infected somebody else. Prior to meeting my wife I kept myself to myself. Even after being married a physical relationship still terrifies me. We always use precautions but I am absolutely terrified of hurting my wife unintentionally. Despite what the doctor's may say about current medical advances making contamination all but impossible, I cannot believe any of them.
26. I am susceptible to illnesses such as shingles, colds and flu. I suffer from exhaustion, lack of concentration and brain fog as a result of the infections. I sleep during the night and I end up having to nap through the day as I suffer from fatigue, which affects me on a daily basis. In or about the early 2000s I suffered from a bad case of shingles, which destroyed my CD4 count. The result of which I had to start daily anti-viral treatment.
27. As a result of shingles, I had to start taking HIV treatment. I refused to take AZT as I was aware how horrendous the side-effects were from the treatment. I would have chosen death over AZT. In fact I resisted any HIV treatment for as long as I could but when my CD4 count dropped significantly I had no choice, but to start the treatment. Approximately 2 or 3 years ago my HIV medication was changed because I started treatment for the Hep C. I am currently taking Efavirenz and Ictastan for HIV, which consists of daily tablets.
28. As previously stated I received vaccinations, which treated Hep A and Hep B.
29. Approximately 3 years ago I was given Interferon and Ribavirin treatment to treat Hep C. The treatment nearly killed me. It was the most brutal treatment I have ever had and I honestly thought I was dying. The first course of treatment was for 13 weeks, but approximately 3 weeks into the treatment I struggled to breathe and function normally. My urine was black. I had never experienced anything like it. This treatment was meant to make me better but it made me 100 times worse.
30. During a routine check up at the [GRO-B] the doctors told me I looked terrible. They conducted tests to find out what was wrong with me. By this point my blood count dropped severely and I was told that I may need a blood transfusion. My doctors took a urine sample, which was black. My consultant, [GRO-B] rang me to tell me that whilst they were carrying out the tests, I should continue with the treatment as normal. I recall that I had enough energy to

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drive home. However, 3 or 4 days later she telephoned in the evening and said that she needed to see me immediately. Unfortunately, I did not have the energy to drive to see her and I believe that if I got into my car, I would have caused an accident. I lay down on the sofa and fully expected to die that night, there was no fight left in me. My sister took me to the hospital the following morning and **GRO-B** stopped the treatment.

31. The Interferon and Ribavirin treatment also affected me mentally. The doctors warned me about the side-effects and I recall bursting into tears on a daily basis. I was extremely emotional during the course of the treatment. It was a horrible experience.
32. Physically I suffered from every symptom listed. I had no bowel movement and it felt like trying to pass barbed wire. I had no energy and suffered from difficulties with breathing. I cannot emphasise enough how hard this treatment was.
33. Approximately 6 to 8 months later, I was given a second course of Interferon and Ribavirin treatment. My doctors told me that the Hep C treatment was clashing with the HIV medication and I had to change the treatment for the HIV. Unfortunately, I had to keep changing my medication for the HIV, which lasted 4 weeks because the treatment I was given kept clashing. It was just as brutal and the treatment was stopped again.
34. Subsequently the doctors advised that I could try a Harvoni treatment, which only consisted of one daily tablet. From this treatment I suffered with headaches, therefore in comparison to previous treatments it was incomparable and seemed like a miracle treatment. The treatment was successful and cleared the Hep C. The HIV treatment that I was on at the time stayed the same and did not clash with the Harvoni treatment.
35. The only difficulties or obstacles that I faced in accessing treatment were the delay in receiving the treatment. I believe that the preconditions were that the sickest patients receive the funding for the treatment first.
36. The infections have been a part of who I am for **GRO-B** years and I struggle to distinguish the health effects of one over the other and majority of the symptoms blur into one.
37. I attend the dentist at the **GRO-B** and as a result I have not experienced obstacles in receiving dental treatment.
38. The infections had an effect on my private, family and social life. Only my immediate family were aware that I had been infected with the above infections. We did not tell anyone out of fear. It was our agreement that we would tell people that I suffered from cancer if I had become critically ill.
39. My first experience of stigma was at school and we were told to keep our toothbrushes separate from everyone else and our towels had to be washed after every shower. I knew

other haemophiliacs who were also infected and because of the stigma we never discussed our infected status outside of our friendship circle.

40. The stigma still exists and I believe that it will never disappear regardless of what this Inquiry finds or what the Government says.

41. I have experienced discrimination at my previous job, [GRO-B] I had worked there for about [GRO-B] years. The company were recruiting and a friend of the family suggested I should apply. It was good comradeship to start with. During this time I was briefly dating a colleague. She knew that I was a haemophiliac and put two and two together and instantly it was all around work that I was carrying these infections. I had no choice but to leave work. I also felt that I had to leave [GRO-B] where I resided at the time. I now only visit [GRO-B] on occasions because my parents live there. My life was threatened and the police were involved.

42. As previously stated, I was told that I had a short life expectancy. I went to college to do 'A' Levels but I did not continue with the education as I thought it would be futile. 22 years later I went to night school to gain an 'Access to Higher Education' certificated, so that I could go to university to study History. I am now studying a Masters Degree in [GRO-B] and I would like to do my PhD afterwards. I believe that had I continued my higher education when I was younger I would have now had a lovely job somewhere probably teaching at a University. But here I am edging on [GRO-B] and I have just gone back into education. The infections really affected my future.

43. I have been affected financially as a result of the infections. I had to leave my job. I am now [GRO-B] years old and I have retired medically. I live on employment and support allowance. I was earning approximately £28,000 a year with a view of a promotion at [GRO-B]

44. I do not have any children as it has never been safe to have them until recently, or so I am told.

Section 6. Treatment/Care/Support

45. The only obstacle that I had experienced was a delay in receiving treatment, as stated above.

46. I have never been offered psychological support or counselling. It's possible that it could have helped. I would never know, as I was not offered it.

Section 7. Financial Assistance

47. I received £20,000 from the Macfarlane Trust (MFT) when I was approximately [GRO-B] years old which, like any other typical [GRO-B] year old, I bought a nice car with.

48. I also received monthly ex-gratia payments until the MFT disbanded. It started as about £500 in the late 1980s by the time it changed to the EIBSS it went up to approximately £1,200 a month.
49. I have also received a Stage 1 payment in the sum of £20,000 from The Skipton Fund. I do not recall when I received this. I recall I had to obtain a letter from my doctors confirming the Hep C infection.
50. The MFT was set up following the 1991 litigation and a solicitor told me to agree to the lump sum payment and the monthly payment. I signed the waiver. As I used to attend Treloar's College and there were many Haemophiliacs there, a representative came to arrange the payments that made the application process straightforward.
51. The Government changed the rules and there is a disparity between the mono-infected and co-infected. There was a lot of pressure to equalise payments. I think it is unfair that people get different amounts. I currently receive £22,000 per infection, but I should be getting £28,000 per infection. I have written to the EIBSS and the standardised reply from them was that they administer the funds and do not make the policies.
52. I am aware that I could apply for extra funds from the MFT but this got progressively harder. I applied for transport but I did not have Motability allowance. Therefore my only experience for applying for extra funds was that my application was refused as I was not buying a Motability vehicle.

Section 8. Other Issues

53. It is unacceptable how many years have been taken away from us. It is wrong on every level. The Government have got away with it because people kept quiet in fear of the stigma.
54. My wife is fantastically angry with the Government. She does not understand how this has happened and how the Government has kept it quiet for so many years and questions how they continue to get away with it.
55. How can you fight the Government when you are between 9 to 16 years old? How can any citizen fight a Government?

Anonymity, disclosure and redaction

56. I wish to be anonymous.
57. I do not wish to give oral evidence to the Inquiry.
58. I understand the reasons behind the need for this Inquiry to ask a set of standard questions but they can in no way convey the impact of what was, I believe intentionally, done to me.

Every person infected or affected have had to devise their own method of surviving this manmade, top down, inflicted catastrophe. And be assured, they have had to do this alone. For the people involved it has become a uniquely intolerable and life destroying situation and survival comes in all forms. For some *it has become an all consuming hunt for the truth of it all; the need to find all of their medical records, to build up a timeline of the events that forcibly brought them to this point.* For myself, survival comes from not looking too closely at it all.

I have been a victim of what I believe to be illegal human experimentation. I have suffered the discrimination of the fearful and ignorant, all stemming from one advert, 'Don't die of ignorance'. I have had to live in the shadow of a half-life, denying myself the freedoms that every person of a free and just society should be able to expect. *To survive this I cannot look at my medical records. I cannot speak of what was done to me and I always keep the secret.* My wife and immediate family are all I can allow to know the truth, I have seen first-hand what happens if the secret gets out.

The danger in all this is 'hope' that finally the truth will come out and justice will finally be done. A failure to do this would decimate yet more lives. Good luck to us all.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed.....

GRO-B

Dated: 18/07/2019